

# **PEDIATRIC EPILEPSY CONSULT NOTE SURVEY RESULTS**

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## Introduction

The Pediatric Epilepsy Clinic at Alberta Children's Hospital (ACH) has implemented an Epilepsy Consult Note given to families in order to improve communication and transparency regarding their visit to the clinic. The goal is to empower families to advocate for their children. The note aligns with the Patient First strategy by providing Patient and Family Centred Care (PFCC) and attempting to improve the patient and family experience.

The note provides parents written information about the child's diagnosis and an emergency rescue plan in the event of a seizure. It also includes a medical summary and a plan for managing the child's seizures. The note helps the families understand the core elements of the child's seizure management in order to communicate important information to doctors and nurses when discussing their child's seizures.

Clinical Quality Metrics (CQM) conducted an evaluation of the parent experience regarding the consult note and the following is a summary of the survey results.

## Method

An online survey (Appendix A) was developed in SelectSurvey software. A PFCC Liaison was consulted during the survey development to finalize the questions and the wording. The survey was administered to parents at the clinic using iPads July 6 - October 7, 2016 and 84 families completed it.

The survey responses were analyzed using Excel and SPSS to provide descriptive results and a comparison of parents who received the note and those who did not.

## Results

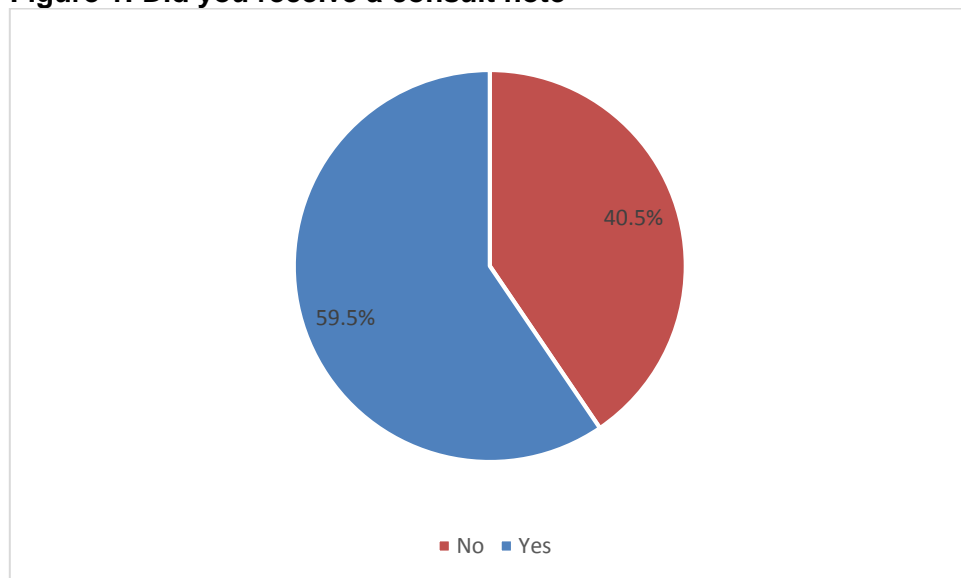
The survey was completed by 84 families and the feedback they provided was largely positive. The parents who were given the consult note at the end of the clinic did not differ from the ones who did not receive one except in terms of being able to name the diagnosis of the child's epilepsy or seizure disorder; parents who received the note were more likely to know the diagnostic name.

The results of each question are presented below.

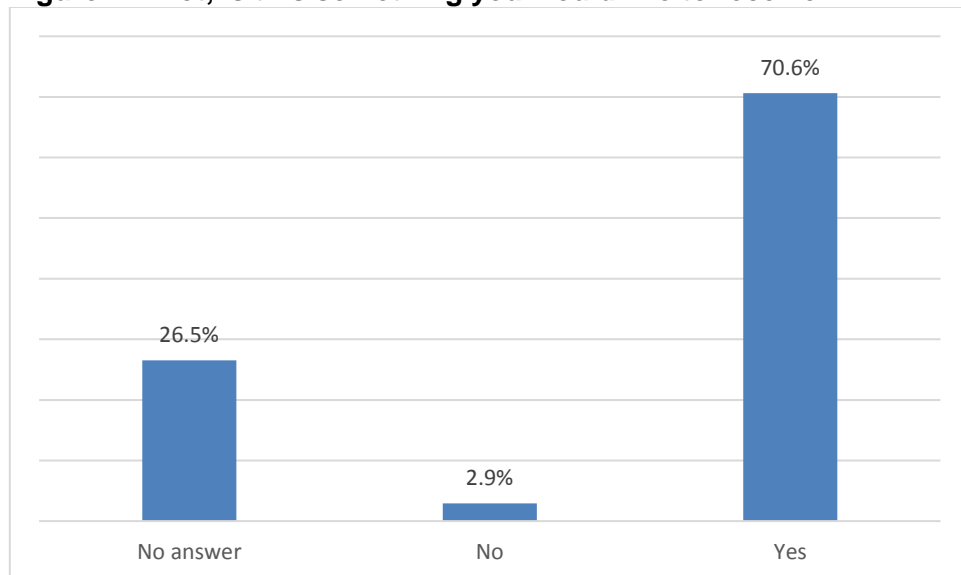
### ***Distribution of consult notes***

As seen in figure 1, more than half of the 84 respondents (n = 50, 59.5%) received the consult note at the end of the family's previous visit to the clinic. Figure 2 displays the distribution of the 34 parents who did not receive the note in terms of whether they would like to receive one after a clinic visit. The majority (n = 24, 70.6%) expressed that they would like to receive the consult note.

**Figure 1: Did you receive a consult note**



**Figure 2: If not, is this something you would like to receive?**



### ***Experience of parents who received a consult note***

A set of questions about their perception and experience of the consult note was given to the parents who received one (n = 50).

Figure 3 shows that a vast majority of parents had read the consult note at the time they took the survey.

**Figure 3: Have you read the epilepsy note?**

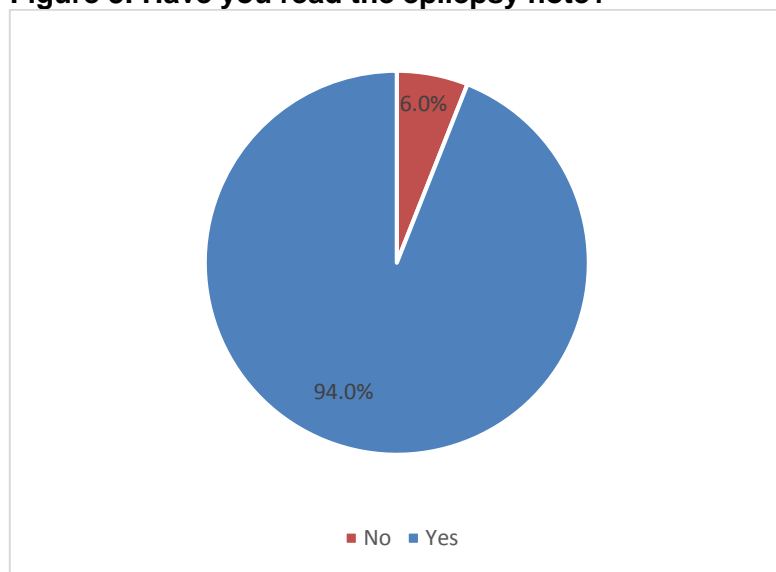
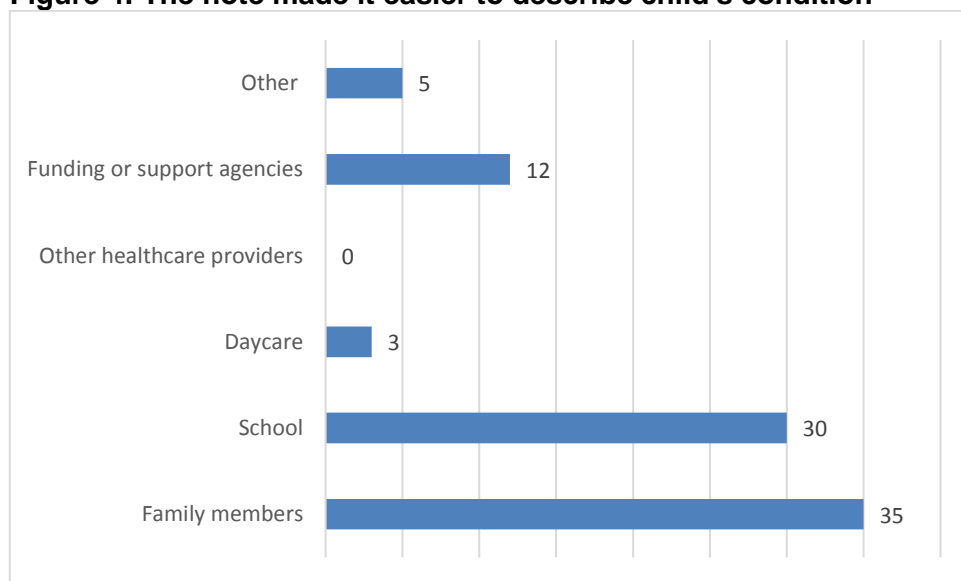


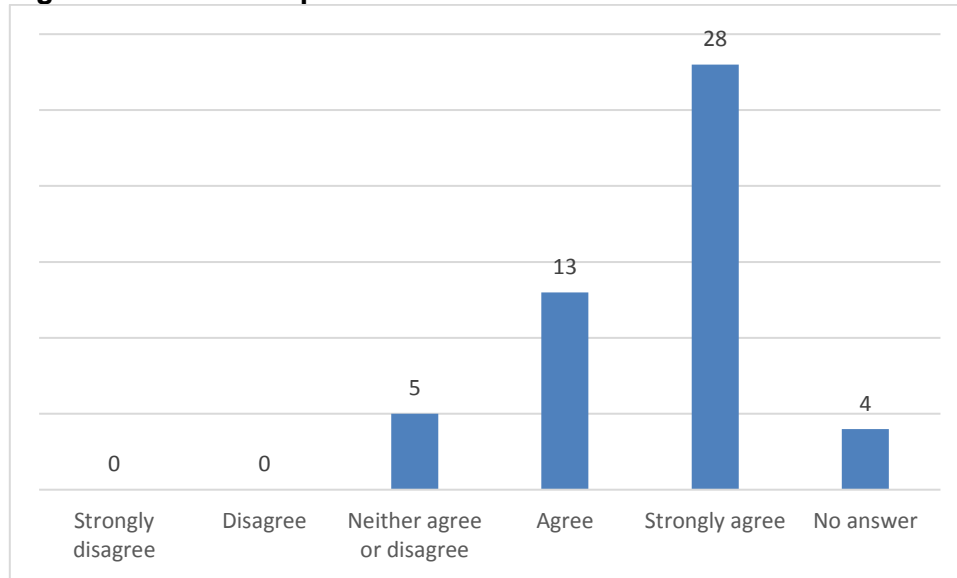
Figure 4 shows that parents found the note helpful when describing their child's condition to others. They reported it as being especially valuable when communicating this information to family members and the child's school.

**Figure 4: The note made it easier to describe child's condition**



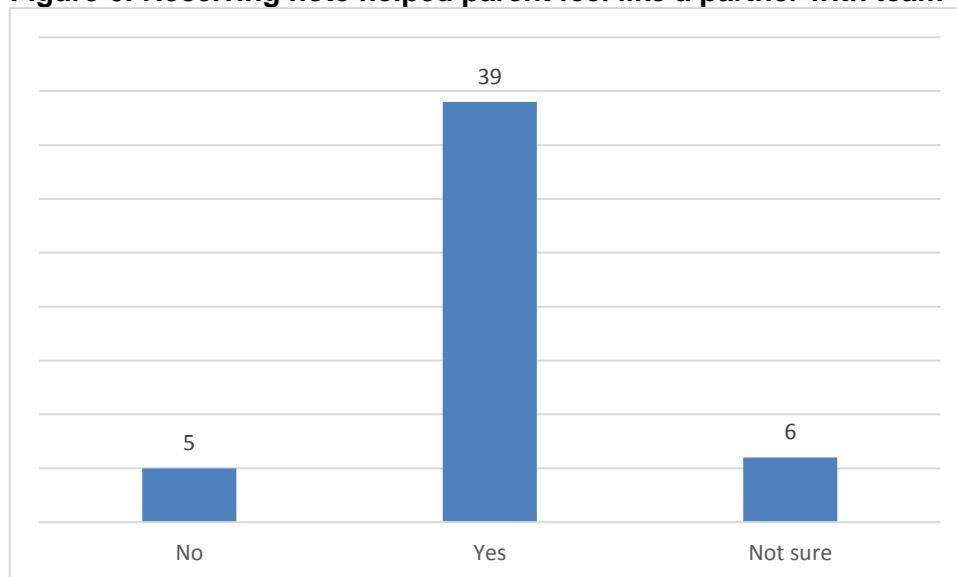
Nearly all the parents who answered the question about whether the note made them feel more confident about the medical and nursing care that their child was receiving either agreed or strongly agreed that this was the case ( $n = 41$ , 89.1%). None of the parents disagreed with the statement.

**Figure 5: Note made parent feel more confident about care received**



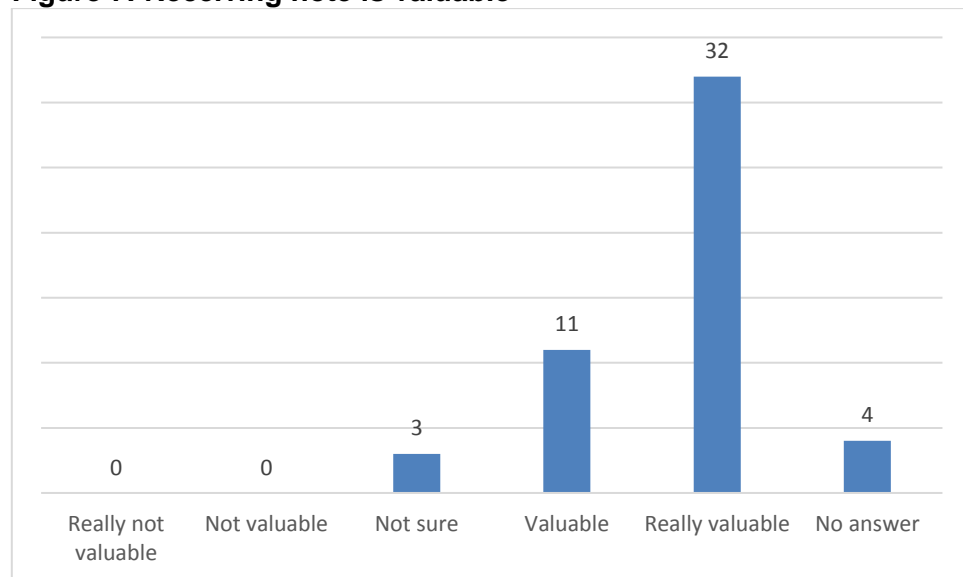
The note was helpful in making more than three quarters (78%) of the parents feel like they were partners with the Epilepsy Clinic Team in caring for their children.

**Figure 6: Receiving note helped parent feel like a partner with team**



Of the 80 parents who answered the question whether they perceived the consult note as valuable, 93.5% reported that they found it either valuable or really valuable.

**Figure 7: Receiving note is valuable**



Parents who were given a consult note were asked if they wanted to add anything else about the note in an open ended format and seven parents provided additional comments. Four comments referred to the usefulness of the consult note as record of the visit and the information discussed; the parents felt that they might not be able to remember all the verbal information due to its volume and the note is helpful to review.

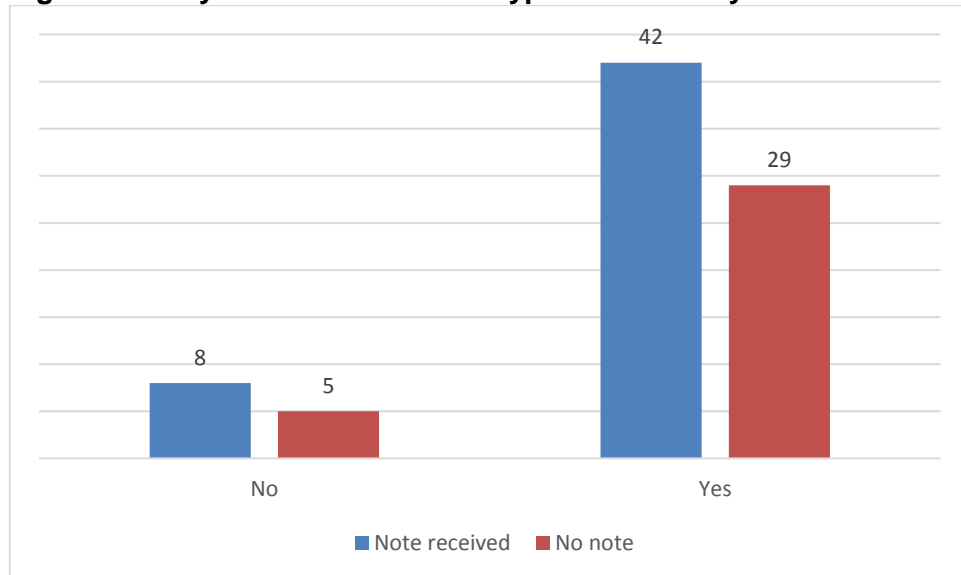
The other respondents provided suggestions such as including more details about issues discussed at the clinic and emailing the note to the parents.

### *Feedback from all parents*

All respondents, whether they received a consult note or not, were asked a series of questions about their knowledge and level of understanding of their children's epilepsy.

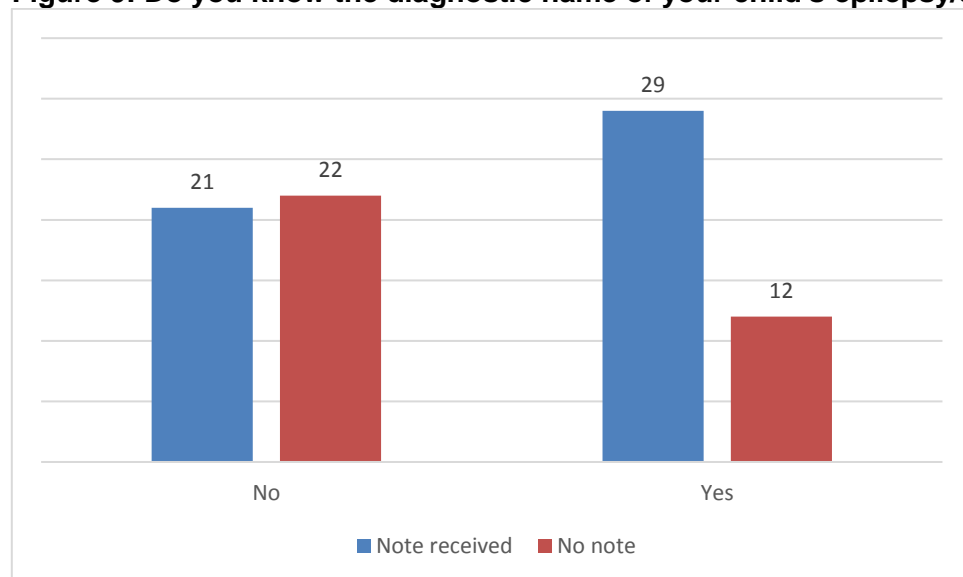
The parents who received the consult note and those who did not reported a similar level of ability to describe the type of seizures their children have experienced with 84.0% and 85.3%, respectively, agreeing that they are able to do so.

**Figure 8: Are you able to name the type of seizures your child has experienced?**



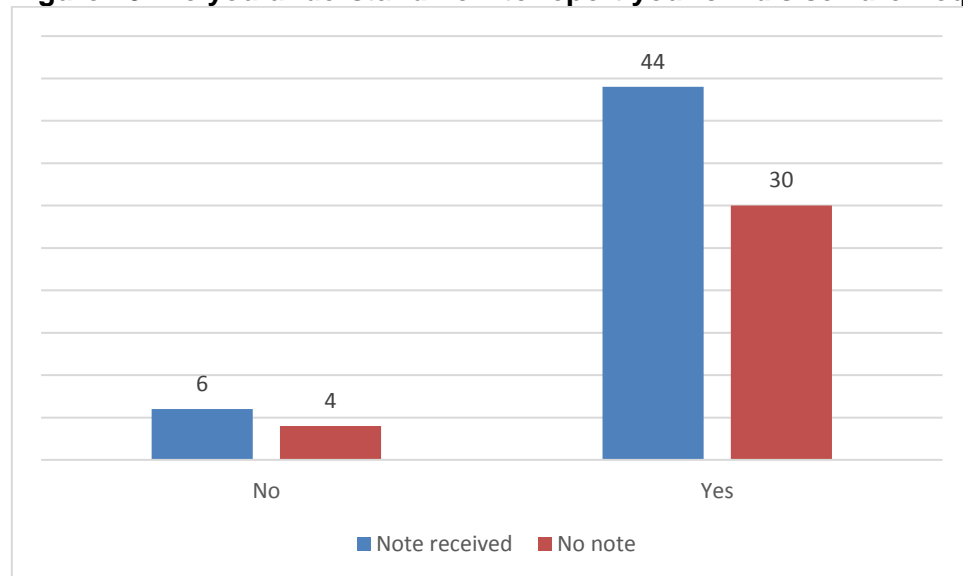
Parents who received the consult note reported knowing the name of the child's epilepsy or seizure disorder more often than parents who did not receive a note. (58.0% vs 35.3%). The difference was statistically significant ( $X = 4.176$ ,  $p = 0.041$ ).

**Figure 9: Do you know the diagnostic name of your child's epilepsy/seizure disorder?**



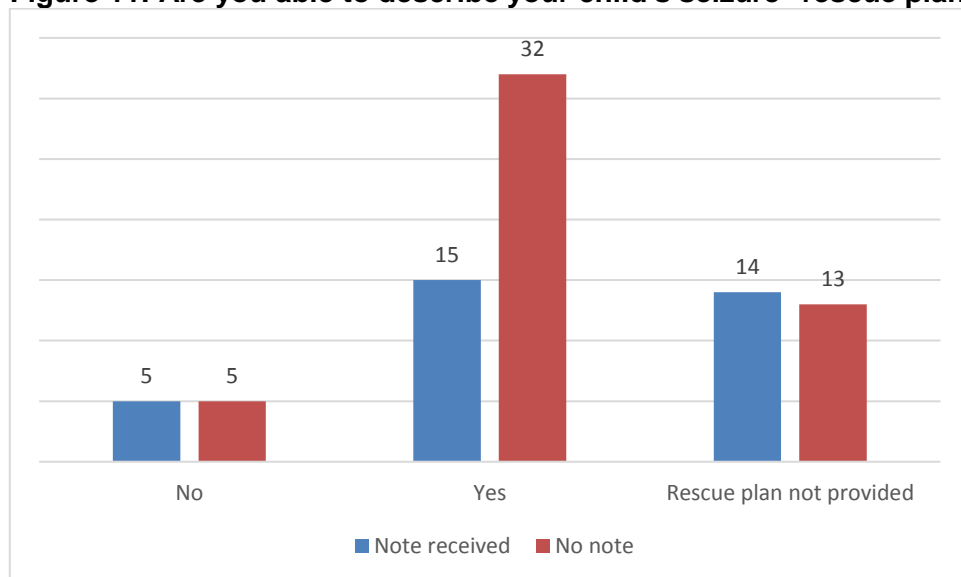
The majority of both groups of parents claimed that they understand how to report the frequency of their children's seizures when asked by a doctor or nurse (88.0% of parents who received a note; 88.2% of parents who did not receive a note).

**Figure 10: Do you understand how to report your child's seizure frequency?**



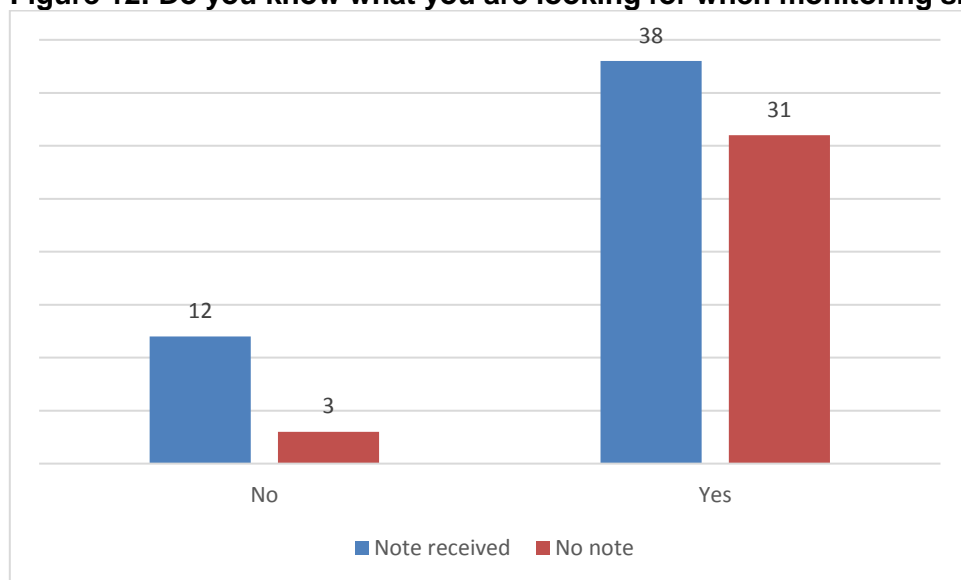
A quarter (26.0%) of the parents who received a consult note reported that a rescue plan was not provided to them; 41.2% of the parents without a consult note did not receive a rescue plan. 64.0% of consult note recipients and 44.1% of non-recipients who had a rescue plan reported that they are able to describe the plan.

**Figure 11: Are you able to describe your child's seizure "rescue plan"?**



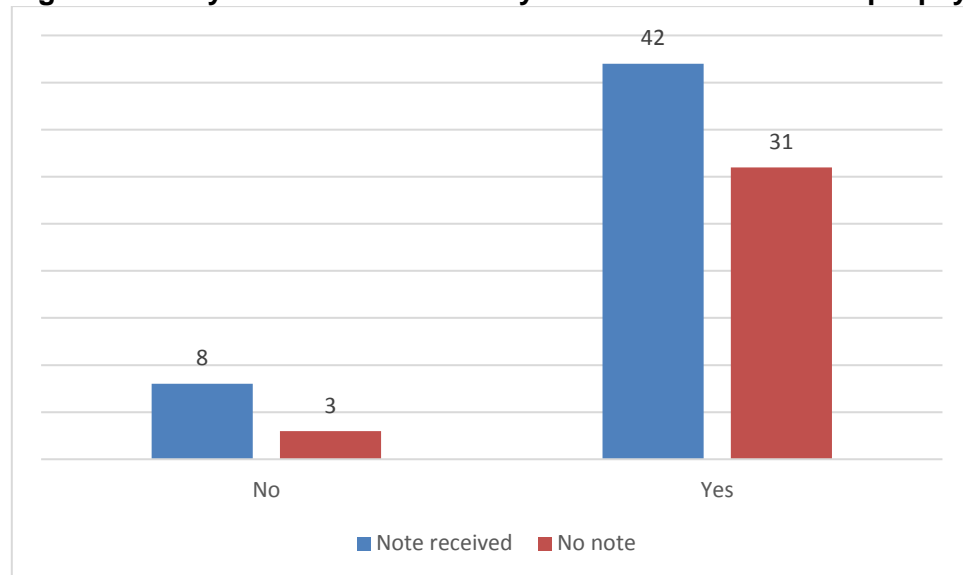
Nearly all the parents who did not receive a consult note (91.2%) reported that they know what they are looking for when monitoring side effects of anti-seizure medications while three quarters (76.0%) of the parents who received the note reported being able to do so.

**Figure 12: Do you know what you are looking for when monitoring side effects?**



The majority of both groups of parents (84.0% who received a consult note and 91.2% who did not) agreed that they understand under what circumstances they should contact the Epilepsy Clinic nurse.

**Figure 13: Do you understand when you should contact the Epilepsy Clinic nurse?**



The survey concluded with an open ended question eliciting additional information about the family's experience at the Neurology Outpatient Clinic of ACH. Fourteen parents took the opportunity to answer this question. Parents commented on how informative the visits are that the note adds value to their experience. Many parents commended the nurses and doctors for their friendliness and willingness to answer questions without rushing the family.

## Conclusion

Overall, the feedback provided by the 84 families who completed the survey was very positive. Approximately 60% of the families had received the consult note and they felt that the note was valuable and helped them communicate about their children's condition with healthcare providers and others who require this information such as schools and daycares. They reported that getting the note contributed to them feeling like partners with the healthcare team. Almost three quarters (71%) of the families who had not received an Epilepsy Consult Note reported that they would like to receive one.

Both families who received a consult note and those who did not were asked a series of questions about their knowledge and understanding of their children's epilepsy or seizure disorder. The two groups were similar in the way they responded and the only statistically significant difference was that the families who received the note were more likely to know the diagnosis name. Both groups reported a high level of understanding of the aspects they were asked about.

The consult note is highly valued by the families and they find it helpful to refer to after appointments. Many respondents commended the healthcare team at the Epilepsy Clinic for their friendliness, helpfulness as illustrated by the following comment by a parent: *"The medical professionals are absolutely the best. We love coming to appointments!"*



## APPENDIX A: PEDIATRIC EPILEPSY CONSULT NOTE – PARENT EVALUATION

### Pediatric Epilepsy Consult Note - Parent Evaluation

Page 1

#### Background

In the last year, the Epilepsy Quality Improvement team at the Alberta Children's Hospital (ACH) have developed an Epilepsy Consult Note for families (or what the clinic team may have simply called the 'Note'). The Epilepsy Consult Note is a printed summary of your child's clinic visit and gives the details of the patient plan. At this point in time, not all families/caregivers are receiving the Epilepsy Consult Note at the conclusion of their clinic visit. Because this is new, we would like to understand from parents/caregivers:

- 1) If you received the Epilepsy Consult Note,
- 2) If you received the Epilepsy Consult Note, what have been the benefits, and
- 3) Your understanding of your child's Epilepsy.

Even if you have not received an Epilepsy Consult Note, we would still like to receive feedback from you.

Sometimes the words used by doctors and nurses to describe a medical condition are different than what families would use. For this reason, we will define a few terms so that we have a common understanding before you complete the survey.

- A **seizure** is what a person does or experiences due to a burst of uncontrolled electrical activity in the brain.
- During a **seizure** a person may shake and become unresponsive to the outside world.
- **Epilepsy** refers to the medical condition in which someone has two or more **seizures** that are not caused by something like fever, head trauma or infection in the brain.
- A **seizure disorder** is just another name for **Epilepsy**.

### Pediatric Epilepsy Consult Note - Parent Evaluation

Page 2

#### Epilepsy Clinic Evaluation Questions

Did you receive a copy of your child's Epilepsy Consult Note at the conclusion of your child's last clinical appointment?\*

- ☐ Yes  
☐ No



Pediatric Epilepsy Consult Note - Parent Evaluation

Page 3

Have you read the Epilepsy Consult Note that you received after your last clinic visit?

- ☐ Yes  
☐ No

Receiving the Epilepsy Consult Note made it easier for me to describe my child's medical needs to:  
Please check all that apply.

- ☐ Family members  
☐ School  
☐ Daycare  
☐ Other health care providers  
☐ Funding or support agencies (eg., FSCD)  
☐ Other, please specify

Receiving the Epilepsy Consult Note has made me feel more confident about the medical and nursing care that my child is receiving.

- ☐ Strongly agree    ☐ Agree    ☐ Neither agree or disagree    ☐ Disagree    ☐ Strongly disagree

Receiving the Epilepsy Consult Note has helped me feel like a partner with the Epilepsy Clinic Team in my child's care.

- ☐ Yes    ☐ No    ☐ Not sure

Do you feel that receiving the Epilepsy Consult Note is valuable?

- ☐ Really valuable    ☐ Valuable    ☐ Not sure    ☐ Not valuable    ☐ Really not valuable

Is there anything else you would like to tell us about the Epilepsy Consult Note that you received?

↑

↓



Pediatric Epilepsy Consult Note - Parent Evaluation

Page 4

Are you able to name or describe the type of seizures your child has experienced?

- ☐ Yes  
☐ No

Do you know the diagnostic name or type of Epilepsy/seizure disorder that your child has been diagnosed with?

- ☐ Yes  
☐ No

Do you understand how to report your child's seizure frequency to a doctor or nurse when asked?

- ☐ Yes  
☐ No

Are you able to describe your child's seizure 'rescue plan'?

- ☐ Yes  
☐ No  
☐ Rescue Plan has not been provided

When monitoring your child to see if they are experiencing side effects from their anti-seizure medication, do you know what you are looking for?

- ☐ Yes  
☐ No

After leaving the Epilepsy Clinic visit, do you understand under what circumstances you should contact the Epilepsy Clinic nurse?

- ☐ Yes  
☐ No

Is there anything else you would like to tell us about your experience attending the Alberta Children's Hospital Neurology Outpatient Clinic?